Studies on therapeutic patient education in chronic diseases : a survey of literature from 1997 to 2004

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STUDIES ON THERAPEUTIC PATIENT EDUCATION IN CHRONIC DISEASES: A SURVEY OF LITERATURE FROM 1997 TO 2004

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Summary

We have tried to describe and analyse the evolution of publications devoted to patient education (PE) and therapeutic patient education (TPE) over a 8 years period.(1997-2004).

Among 945513 studies published on chronic diseases, 3 types of analyses have been undertaken : evolution of PE publications, relative evolution of PE and TPE publications, evolution of types of publications (descriptive, experimental, meta-analysis).

Our study shows that PE publications have clearly increased over the years , indicating that PE practice is more and more considered of scientific interest.

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1. Introduction

Chronic and long duration diseases need to be managed on the long term by both medical therapy and change in life style.

The physician often has to educate patients for the treatment, to transfer some of his competences, to be emotionally involved, to ensure a social and psychological support (2).

Therefore the evolution of health concept, in all its bio-psycho-social dimensions, has developed, around chronic disease and those of long duration, the education of the patient to self-management both of the disease and the therapy (i.e. PATIENT EDUCATION more recently named :THERAPEUTIC PATIENT EDUCATION –TPE), in order to improve the patient health status and to delay the manifestation of complications, thus reducing costs of Public Health Service, length of hospital stays and drug consumption (3) (4).

According to the World Health Organization (1998), Therapeutic Patient Education is more a set of structured activities which consists in "helping the patient and his family to acquire knowledge and competencies on the disease and its treatment, in order to better collaborate with the caregivers, and to improve his quality of life"(4)

The aim of this research is to characterize the development of patient education (PE) practices and research, by comparing the evolution of publications on chronic diseases, and among them, those on patient education during a 8 years period (1997 – 2004). Another objective is to identify the development of TPE programmes among PE activities, as an evolution of PE practice, following the WHO recommandations.

2. Methods

The study was carried out by 4 analyses: 1)description of publications on chronic diseases, globally and by type of publications, and of publications on patient education (PE) , by anatomic systems and medical specialties; 2) evolution of the yearly rate of PE publications on a 8 years period; 3)

evolution of the use of the terms: PE and TPE programme; 4) distribution of types of publications on PE for the main chronic diseases.

2.1. Range of studied diseases: considering the definition of chronic disease given by the World Health Organization, a list of chronic pathologies has been preliminary drawn up after consulting the following sources: a) Conn's "Current therapy" 52nd edition b) Washington "Manual of medical therapy" 28 hth edition; c) Stedman's Pocket Medical Dictionary d) Oxford Dictionary.

The various diseases have been grouped, to avoid confusion in interpreting the data, according to the different anatomic systems that are affected by such diseases.

2.2. Sources: we have consulted the sites "Pub-Med" and "Eric Database Search Options", in order to identify international studies on main chronic diseases (i.e. diabetes mellitus) published from 01/01/1997 to 12/31/2004. Subsequently, we have looked for publications on chronic diseases where the key-word "patient education" was mentioned (i.e. - key–word: Diabetes mellitus and patient education) .In a second time, we have tried to identify more precisely publications using the term: therapeutic education programme (key-word :TPE programme) ,in order to observe the evolution of this educational practice.

2.3. Type of studies: Three types of studies were identified: a**)** descriptive studies (preexperimental); b) randomized controlled trials (experimental studies); c) meta-analyses.

3. Results

3.1. Place of PE in studies on chronic diseases.

Overall, on the 8 years period, 945.513 studies on chronic diseases were identified. Among them, 8.985 studies on PE (0.95% of the total) were counted (Table 1).

The 4 disciplines more invested in PE activities are : 1) endocrinology (2,11% of the total number of 1997-2004 studies), 2) pneumology (2,04%), 3) nephrology and urology (1,00%), 4) neurology and psychiatry (0,79%). On the opposite the 4 disciplines which seem to develop less PE activities are respectively : rheumatology (0,76%), cardiology (0,67%), gastroenterology (0,27%)and haematology (0,21%). But this ranking appears somewhat different when considering the diseases

for which PE activities are organized : the studies on bronchial asthma including patient education represent 3,79% of the total number of the studies, followed by diabetes (2,82%), anxiety (2,24%), and congestive heart failure (1,33%).

3.2. Evolution of the rate of PE publications on a 8 years period

The data related to PE publication production during the period taken into account (table 2) show an important increase in some systems : Haematology (+79.1% 2004 total:43), Digestive (+ 44.2% 2004 total:44), a moderate increase in others systems: Genitourinary (+39.7% 2004 total:65), Cardio-vascular (+36.6% 2004 total: 248), Endocrine (+32.5% 2004 total: 477), a slight increase: in Locomotor and rheumatology (+25.2% 2004 total:144) and Nervous and psychiatry (+29.5% 2004 total:355) , but nearly no increase in respiratory system (+9.6% 2004 total:187). It should be noticed that the progression of the publications on PE is more important than that of the systems (except respiratory and dermatology) for the same 8 years period.

3.3.Evolution of the use of the terms PE and TPE

Moreover, after having compared the studies using the key-words “TPE programmes” from the global number of publications on “PE” (PE+TPE), we have noticed an important difference both in number and in percentage (Table 3). Particularly, we have deduced that the most significant data concern the publications dealing with the following systems: respiratory system (TPE programme n=81; PE n= 1299, TPE/PE=6,23%), nervous system and psychiatry (TPE programme n=86; PE n=1971; TPE/PE=4,36%), cardiovascular system (TPE programme n=50; PE n=1404; TPE/PE=3,56%), endocrine system (TPE programme n=85; PE n=2684; TPE/PE= 3,16%), genito – urinary system (TPE programme n=18; PE n=342; TPE/PE=5,26%).

3.4 Distribution of types of publications in PE

Three types of publications were identified: descriptive studies, random control trials (RCT) and meta-analyses. Although RCT is not always the best design for studies on PE, it is the most widely used keyword when addressing strictly experimental design. In publications on chronic diseases,

descriptive studies appear 900347 times (95.2% overall), RCT 41685 times (4.4%) and meta-analyses 3481 times (0.36%).

4 Discussion

4.1. Place of PE in studies on chronic diseases

Although it has been demonstrated that patient education offers advantages in terms of reduction of hospitalizations for crisis, days of absence from job/school, social and psychological costs, time of emergence of complications (4,5,6,7,8,9), we ask ourselves why in some diseases (i.e pernicious anaemia, alimentary allergy, valvular insufficiency…) experiences of PE activities have not been already reported.

A possible explanation could be that education of the patient is not yet acknowledged in many specialties as a scientific activity. The majority of physicians has not been trained in patient education methodology during their studies and many practitioners consider that PE is more related to nursing role, and consequently, less "scientific". In fact, as PE is an activity frequently delegated by the physicians to the nurses and other paramedics, it may be more or less mentioned in scientific studies. Moreover, nursing and other allied health professions studies on PE are not frequently indexed in medical data bases.

4.2. Evolution of the use of the terms PE and TPE

When the term "TPE" was introduced officially in 1998 (4), it was expected to gradually replace "PE", because of its focus on care givers specific responsibility. Obviously, this has not happened, as TPE represents only 6% of the used keywords. This important difference can be explained considering that the term: "programme" is very specific. According to WHO 1998 recommendations on therapeutic patient education, a TPE programme is a set of organized activities , generally addressed to groups of patients; it is based on formal educational objectives, with selected teaching techniques and is comprehensively evaluated. On the opposite, the term "patient education" may refer to a less formal type of education, frequently delivered individually at bedside or during a consultation. This could explain why there is a greater number of publications using the

term PE, instead of TPE, which seems to correspond better to the actual reality in hospitals and other care settings. Another possible explanation could be to consider that the term TPE is not interpreted in the same way by all researchers. Sometimes, indeed, TPE (according to WHO definition) is meant as a "transfer" of competences (4). In other cases, it could be meant as transmission of information and counseling .

4.3. Distribution of types of publications in PE

Analysing the data concerning a probable increase of randomized studies and meta – analyses of the period 1997 – 2004, we have noticed that in a few number of systems an increase is evident (COPD 33%, anxiety 100%, depression 100%, congestive heart failure 100%, hypertension 100%, arthrosis 100%, rheumatoid arthritis 100%, obesity 100%).

However ,this study demonstrates the growth of such studies in the last years ,despite the difficulty to carry out such researches, that require application of more complex methodologies than those utilized in more simple studies (10).

5. Conclusions

Although in many publications the terms used to describe patient education are not only "patient education" or "therapeutic patient education" ,but sometimes : patient instruction, patient teaching, patient counselling" or in psychiatry:" psycho-education", there is undoubtedly a growth of the number of publications on patient education, indicating a corresponding rise of attention paid by the scientific community to this activity. Our study brings a mobile picture of the development of patient education in care and long term follow-up of chronic diseases. But this picture is most probably partial, due to the fact that so many "professional publications" (journals, reports, booklets) describing PE and TPE programs and educational documents cannot be found by consulting medical databases.

This study also shows the development of the TPE practice, ie structured programmes delivered by multi professional teams, according to the WHO definition. It seems highly probable that this model of patient education will be predominant in the future. The studies on PE are in majority of

descriptive and pre-experimental type. There are relatively few randomized control trials and even less meta –analyses, probably because of the difficulty encountered by the researchers to apply to PE experiences the "classical" models of protocols used for bio-pharmacological research. In fact, PE is by no way comparable to the application of a therapy: it determines psycho-cognitive modifications , a potentiality to change the patients' behaviours, complex multifactorial phenomena with no certainty of when and how this change will occur.

Finally, our study stresses the importance of encouraging and supporting research on PE , despite the methodological difficulties of this type of research. Although PE and TPE practice and activities have increased and improved during the last years, further improvement needs more hard evidence and clear theories and recommendations . We need to know what works, how it works, and how to be more efficient.

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Table 1: Distribution of studies on chronic diseases (CD) and on patient education (PE) during the 1997-2004 period

ANATOMIC SYSTEMS	Total • studies CD	Total • studies PE	% å PE. / å CD
Endocrine system	**127.145**	**2.684**	**2,11%**
Respiratory system	**63.374**	**1.299**	**2,04%**
Genito -urinary system	**34.164**	**342**	**1,00%**
Nervous system, special apparates and psychiatry	**248.771**	**1.971**	**0,79%**
Dermatology	**12.283**	**95**	**0,77%**
Locomotor system and rheumatology	**107.800**	**825**	**0,76%**
Cardiovascular system	**207.406**	**1404**	**0,67%**
Digestive system	**86.475**	**240**	**0,27%**
Haematology	**58.095**	**125**	**0,21%**
OVERALL	**945.513**	**8.985**	**0,95%**

Table 2: Evolution of the rate of annual publications on PE over the 8 years period.

SYSTEMS		1997	1998	1999	2000	2001	2002	2003	2004	Progression 1997-2004
Respiratory	**PE**	154	143	155	145	185	157	173	187	**33 (+ 9,6%)**
	CD	6432	6769	7147	7756	8187	8827	9450	9672	**3.240 (+20,1%)**
Nervous and Psychiatry	**PE**	193	177	211	238	255	267	275	355	**162 (+29,5%)**
	CD	25756	27076	28834	30536	31882	32907	35661	37947	**12.191 (+19,1%)**
Cardiovascular	**PE**	115	154	169	150	163	191	214	248	**133 (+36,6%)**
	CD	19780	20563	22104	23477	24309	25558	27839	29269	**9.489 (+19,3%)**
Locomotor and Rheumatology	**PE**	86	86	108	86	111	100	104	144	**58 (+ 25,2%)**
	CD	11313	11833	12470	12568	13541	14902	15433	16561	**5.248 (+18,8%)**
Dermatology	**PE**	8	11	15	13	9	12	15	12	**4 (+20,0%)**
	CD	1255	1289	1349	1438	1494	1627	1901	1984	**729 (22,5%)**
Haematology	**PE**	5	14	8	14	12	12	17	43	**38 (+ 79,1%)**
	CD	6604	7085	6727	7273	7133	7795	8137	7870	**1.266 (+8,7%)**
Digestive	**PE**	17	28	41	25	25	26	34	44	**27 (+ 44,2%)**
	CD	8886	9589	9942	10341	10733	11474	12212	12975	**4.089 (+18,7%)**
Endocrine	**PE**	243	265	280	350	306	362	401	477	**234 (+32,5%)**
	CD	11931	12646	13335	14406	16053	17963	19583	22224	**10.293 (+30,1%)**
Genito-urinary	**PE**	28	49	37	27	34	51	51	65	**37 (+ 39,7%)**
	CD	3635	4102	4125	4239	4323	4890	5336	5453	**1.818 (+20,0%)**

Table 3: Evolution of the use of terms PE and TPE between 1997 and 2004

		YEAR OF PUBLICATION								
		1997	**1998**	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**	**• %**
Global	TPE	31	47	49	29	49	46	60	75	**386**
	PE	849	927	1024	1048	1100	1178	1284	1575	**8985**
All Systems (PE+TPE)	TPE/PE %	3,65	5,07	4,78	2,76	4,45	3,90	4,67	4,76	**4,29**
Respiratory Syst.	TPE	12	12	7	4	11	5	12	18	**81**
	PE	154	143	155	145	185	157	173	187	**1299**
	TPE/PE %	7,79	8,39	4,51	2,75	5,94	3,18	6,93	9,62	**6,23**
Nervous Syst and Psychiatry	TPE	3	11	6	8	14	12	17	15	**86**
	PE	193	177	211	238	255	267	275	355	**1971**
	TPE/PE %	1,55	6,21	2,84	3,36	5,49	4,49	6,18	4,22	**4,36**
Cardiovascular Syst.	TPE	6	4	7	2	2	10	10	9	**50**
	PE	115	154	169	150	163	191	214	248	**1404**
	TPE/PE %	5,21	2,59	4,14	1,33	1,22	5,23	4,67	3,62	**3,56**
Locomotor Syst and Rheumatology	TPE	4	9	13	2	10	3	6	13	**60**
	PE	86	86	108	86	111	100	104	144	**825**
	TPE/PE %	4,65	10,46	12,03	2,32	9,00	3,00	5,76	9,02	**7,27**
Dermatology	TPE	0	0	0	0	0	0	0	0	**0**
	PE	8	11	15	13	9	12	15	12	**95**
	TPE/PE %	0	0	0	0	0	0	0	0	**0**
Haematology	TPE	0	1	1	0	1	0	0	0	**3**
	PE	5	14	8	14	12	12	17	43	**125**
	TPE/PE %	0	7,14	12,5	0	8,33	0	0	0	**2,40**
Digestive Syst.	TPE	0	0	1	0	0	0	2	0	**3**
	PE	17	28	41	25	25	26	34	44	**240**
	TPE/PE %	0	0	2,43	0	0	0	5,88	0	**1,25**
Endocrine Syst.	TPE	5	8	11	13	8	11	11	18	**85**
	PE	243	265	280	350	306	362	401	477	**2684**
	TPE/PE %	2,05	3,01	3,92	3,71	2,61	3,03	2,74	3,77	**3,16**
Genito-urinary Syst.	TPE	1	2	3	0	3	5	2	2	**18**
	PE	28	49	37	27	34	51	51	65	**342**
	TPE/PE %	3,57	4,08	8,10	0	8,82	9,80	3,92	3,07	**5,26**